



TRAUMATIC BRAIN INJURY ADVISORY COUNCIL

Date: December 12, 2007

Time: 10:00am-1:00 pm

Location: Div. of Public Health

TYPE OF MEETING		Quarterly Meeting		
FACILITATOR		Marilyn Lash, Chairperson		
ATTENDEES				
NAME	PRESENT	NAME	PRESENT	
(Council Members)				GUESTS
Marie Britt	<input type="checkbox"/>	Holly Riddle	<input type="checkbox"/>	Jim Swain for Jo Perkins
Spencer Clark	<input type="checkbox"/>	Sharon Rhyne	<input checked="" type="checkbox"/>	Carol Ornitz
Michele Elliott	<input checked="" type="checkbox"/>	Scott Sagraves	<input type="checkbox"/>	Susan Fewell
Sandra Farmer	<input checked="" type="checkbox"/>	Robert Seligson	<input type="checkbox"/>	Jennifer Hiemenz-CDL
Martin Foil	<input type="checkbox"/>	Elsie Siebelink	<input checked="" type="checkbox"/>	Joe Polich UNC-CH
Travis Glass	<input checked="" type="checkbox"/>	Tom Winton	<input checked="" type="checkbox"/>	Nancy Espinoza
Flora Hammond	<input checked="" type="checkbox"/>		<input type="checkbox"/>	Debbie Reinhartsen -CDL
Tonia Harrison	<input checked="" type="checkbox"/>	Staff to Council	<input checked="" type="checkbox"/>	Becky Edmondson-CDL
Holli Hoffman	<input type="checkbox"/>	Sandy Ellsworth	<input checked="" type="checkbox"/>	Tami Guerrier for Flora Hammond
Steve Hooper	<input checked="" type="checkbox"/>	Jan White	<input checked="" type="checkbox"/>	
Ana King	<input checked="" type="checkbox"/>		<input type="checkbox"/>	
Marilyn Lash	<input checked="" type="checkbox"/>		<input type="checkbox"/>	
Chuck Monnett	<input checked="" type="checkbox"/>		<input type="checkbox"/>	
Liz Newlin	<input checked="" type="checkbox"/>		<input type="checkbox"/>	
Patrick O'Brien	<input type="checkbox"/>		<input type="checkbox"/>	
Grey Powell	<input checked="" type="checkbox"/>		<input type="checkbox"/>	
Jo Perkins	<input type="checkbox"/>		<input type="checkbox"/>	

1. Agenda topic: Welcome, Introductions

Marilyn Lash

Discussion	Sharon Rhyne reported that Valerie Russell is the new head of the Injury and Violence Prevention Branch of DPH. Ms. Russell is in training for her new job and will attend a Council meeting at a later date.		
Conclusions			
Action Items	Person(s) Responsible	Deadline	

2. Agenda topic: Meeting Dates

Marilyn Lash

Discussion	She asked members if they preferred to meet on Dix campus or at the Public Health offices. The group voted to meet again at the NC Division of Public Health on Six Forks Rd.		
Conclusions	The Council's meeting dates for 2008 are March 12, June 11, September 10 and December 10. The meetings will be held at the NC Division of Public Health on Six Forks Rd. if possible		
Action Items	Person(s) Responsible	Deadline	

3. Agenda topic: Administrative Issues:

Marilyn Lash

Discussion	<ul style="list-style-type: none"> <u>Vice Chair</u>: Ms. Lash reported that she asked Jo Perkins if she would be interested in serving as vice chair of the Advisory Council and Ms. Perkins accepted the nomination. Ms. Lash moved to nominate Ms. Perkins as vice
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	<p>chair. Ms. Rhyne seconded. The motion passed</p> <ul style="list-style-type: none"> • <u>A Council membership list</u> was circulated to ensure accurate information. Two family member positions are presently open. Carol Ornitz and Linda Herbert have been nominated for these positions. The Council still needs to fill slots representing veteran affairs, Dept of Social Services and an LME. The DMA slot has been filled by Marie Britt. Additionally, committee lists were circulated and members were encouraged to join committees. • <u>Brain Injury Fact Sheet:</u> Dr. Hammond had some suggestions for revisions and the revised fact sheet is now on the DMH website. The Fact sheet was circulated and members are asked to please use as needed. • <u>Meeting Minutes:</u> Ms. Lash would like to update the procedure for distribution of minutes. Minutes should be completed within 2 weeks and a to-do list will then be generated from the minutes. • <u>Work Plan:</u> Ms. Lash would like the Council to have a work plan for 2008. North Carolina is behind most other states for brain injury service provision and the Council needs to be action oriented and use the tools which have been developed effectively. All members need to be accountable for outcomes and to help the Council be more proactive. • <u>Council Member appointments:</u> Sharon Rhyne, Elsie Siebelink and Steve Hooper's terms are up and they need to be re-appointed. Sandy Ellsworth and Ms. Lash will follow up and confirm by January 15 and try for resolution by January 30. Members who have a brain injury need to complete a release form to allow them to be identified as survivors on the DMH website. These were distributed. • <u>Council Letterhead:</u> Ms. Lash feels there needs to be letterhead for the Council and is working on designing this which will include the names of the Council members. • <u>Administrative Support:</u> Ms Lash will discuss the need for Administrative Support with Flo Stein. 						
Conclusions	Jo Perkins will serve as Vice Chairperson of the TBI Advisory Council						
Action Items							
<ul style="list-style-type: none"> • Follow up on Council Memberships • Ms Lash will discuss the need for Administrative Support with Flo Stein. 	<table border="1"> <thead> <tr> <th>Person(s) Responsible</th><th>Deadline</th></tr> </thead> <tbody> <tr> <td>Sandy Ellsworth Marilyn Lash</td><td>1-30-08</td></tr> <tr> <td>Marilyn Lash</td><td></td></tr> </tbody> </table>	Person(s) Responsible	Deadline	Sandy Ellsworth Marilyn Lash	1-30-08	Marilyn Lash	
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Marilyn Lash							

4. Agenda topic: DMH Lead Agency report

**Sandy Ellsworth
Janice White**

Discussion	<ul style="list-style-type: none"> • The TBI money was not allocated to the Division this year in the manner that is has been before. Continuation funds which support some service options and the contacts were allocated as normal. Other funds (last year 1.4 million) were allocated directly to the LMEs. Funds were allocated in a lump sum to the LMEs and not allocated to specific target areas such as TBI. The Division continues to receive requests from the LMEs for additional funding. TBI providers such as ReNu Life are having financial
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difficulty. ReNu Life is licensed as home for the aged; like the old rest home criteria. ReNu Life is serving approximately 33 TBI consumers at present in their long term care facility and another 10 in group homes. With changes in service definitions, the hours of support paid have been drastically reduced. There is no state Medicaid service definition which serves TBI appropriately. If a consumer gets services under MH or SA, they must have severe and persistent symptoms. State Medicaid ideally would have a service definition that covers the needs of individuals with TBI. Ms. Ellsworth has reported to Spencer Clark that three TBI service providers may be lost if they do not receive adequate funds. There is a possibility of receiving \$500,000. Ms. Lash asked Flo Stein to attend today's meeting but she had another commitment.

- It was discussed that the Council write each of the LME directors to reiterate that they are responsible for TBI services. These letters should make a strong statement to LMEs that the Council is appointed by Governor and has oversight for TBI.

Ms. Rhyne asked if the letters should mention the specific amount received last year for TBI. Ms. Ellsworth stated that over 1/3 of the LMEs have single stream funding which means they make independent decisions regarding distribution of money. Carol Ornitz suggested that the Council could analyze outcomes for the previous years looking at money spent and numbers of consumers served. Ms. Lash requested a summary report of expenditures for the year. Steve Hooper cautioned the Council as this may appear to conflict with some of the findings of the Needs Assessment. The Council may request a report from the LMEs regarding spending on TBI and numbers served.

- Ms. Lash asked if there are any established criteria for TBI money allocation. She would like to see a priority of needs listed for access to funds.
- Ms. Lash asked what is needed to get a new service definition for TBI. Ms. Ellsworth reported that DMH and DMA are in process of writing 4 waivers and a TBI waiver.

Ms. Ellsworth suggested that a subcommittee is needed and that Marie Britt, from DMA would be a valuable addition to discuss the waiver and service definitions. There is not an answer regarding the match that will be required for the TBI Waiver.

Ms. Lash asked if writing a new service definition will allow the use of the larger ABI definition, rather than the TBI definition. Steve Hooper stated that there is little opportunity to open the door to change definitions, so if there is a chance he recommends that we promote the most expansive definition as there may not be another opportunity for a long time. The Council has spent a lot of time reviewing definitions. It was stated that the Council needs to start legislative action as soon as possible to stop TBI service providers from going out of business. ReNu Life is not the only program being affected. Other agencies such as Person County and Lutheran Family Group homes are having financial difficulties. Short term funding will help but long term solutions are needed. Dr. Hooper feels we need to get the service definitions clarified.

	<p>Council members discussed that they may want to meet with Dr. Lawrence, Medical Director of DMA and other key individuals to promote a TBI waiver.</p> <p>Sandra Farmer asked how supporting the Money Follows the Person Waiver will affect the TBI waiver.</p> <p>Council requested to see current Medicaid and state service definitions specifically for TBI. Ms. Ellsworth reported that there is no current definition and recommended research to find other states' service definitions. Ana King offered to get definitions from other states.</p> <p>Dr. Hooper suggests that we start with a joint meeting with Mr. Moseley and Ms. Stein to clarify the Council's next steps. Ms. Ellsworth was asked to set up an appointment with Ms. Stein by the end of January. Ms. Lash, Ms. Farmer, Ms. Ornitz, Ms. Rhyne and possibly Linda Herbert will be at the meeting.</p> <ul style="list-style-type: none"> • The Council needs a sheet of talking points so all have a unified message. Ms. Ellsworth was asked to draft a one page Talking Point paper which Ms. Lash will further develop. This should get to Ms. Lash by December 15. • Ms. Ellsworth reported that DD is the only population that does not have to meet a severe and persistent symptoms requirement, therefore it is advantageous for TBI to remain part of DD. • Ms. Farmer brought Ohio and Florida Needs Assessments and recommendations which the Council may review. • Ms. Lash and Ms. Ellsworth have been working on the State Plan. Ms. White will include prevention points in the plan. Ms. Ellsworth has been attending the Governor's task force on veteran's issues. • <u>Prevention</u>: Ms. White stated that the CDC is working with BIAA on brochures regarding falls in the elderly and TBI identification. These materials should be ready by March of 2008. They have done focus groups and the preview is on the CDC website. • Ms. White has a meeting at the Division on Aging to coordinate prevention activities. • An injury prevention survey will be conducted across NC to see what type of injury prevention programs are going on now in NC. This will provide opportunities for greater TBI prevention. 						
Conclusions							
Action Items	<table border="1"> <thead> <tr> <th data-bbox="1049 1638 1385 1669">Person(s) Responsible</th><th data-bbox="1385 1638 1549 1669">Deadline</th></tr> </thead> <tbody> <tr> <td data-bbox="1049 1669 1385 1791"> Marilyn Lash Sandy Ellsworth Sandy Ellsworth Sandy Ellsworth </td><td data-bbox="1385 1669 1549 1791"> 12-15-07 3-12-08 </td></tr> <tr> <td data-bbox="1049 1791 1385 1822"></td><td data-bbox="1385 1791 1549 1822"></td></tr> </tbody> </table>	Person(s) Responsible	Deadline	Marilyn Lash Sandy Ellsworth Sandy Ellsworth Sandy Ellsworth	12-15-07 3-12-08		
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Marilyn Lash Sandy Ellsworth Sandy Ellsworth Sandy Ellsworth	12-15-07 3-12-08						
Council will send out a letter to all LMEs A meeting will be arranged with Flo Stein and Council Representatives Talking points on TBI and services in NC will be developed Criteria for expenditure of TBI money will be provided							

5. Agenda topic: Guest Speakers reporting on Needs Assessment Steve Hooper and staff of CDL

Discussion	<p>Steve Hooper introduced guests from the Center for Development and Learning for the report on the recent Needs Assessment. Initially, there was going to be \$200,000 and a year for the assessment, but the funding was changed to \$50,000 and the time reduced to 3 months therefore the report was condensed. A PowerPoint presentation was given to the Council members to review data collected from a number of sources, including the Department of Public Instruction, Vocational Rehabilitation, Project STAR and Emergency Department data etc. There is still some data to be gathered. The numbers are underreported. A more expansive needs assessment is necessary to catch mild injuries, military injuries and other brain injuries that are under reported. The current data shows that 50% of consumers with TBI report that they need mental health assistance. 64% were injured after age 22 and would not qualify for CAP MR/DD services. Average age when injured = 30.1 years of age. 50% say they need behavioral supports. 50% need in home or respite services.</p> <p>Ms. Lash requested that Ms. Ellsworth fast track the review and approval of the report by the Division so that Council members can start to use the data.</p> <p>Travis Glass pointed out that most survivors do not know what an LME is, and there is a need for more information to go out so survivors and families will understand how to get services. Also, LME staff is not familiar with TBI and more education is necessary so LMEs will reach out to the TBI population.</p>				
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6. Agenda topic: TBI Fact (Tip) Sheets Sandra Farmer

Discussion	<p>Ms. Farmer reported that this committee is working on tip sheets about brain injuries from Transportation, Sports, Falls, Violence and Recreation. Each will include a story of a survivor and pertinent data. Ms. Farmer is working to get data on costs for mild, moderate and severe injuries including cost information from life care plans. The fact sheets (first 3) will be ready mid-January. Ms. Farmer reported that the federal TBI act has been re-authorized and 6 bills related to military have passed. The concussion study has been completed at UNC on football injuries and she will be getting data from that study. Ms. Lash is working on a draft of a fact sheet on Acquired Brain Injury and will have a draft by January 15.</p>				
Conclusions					
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7. Agenda topic: Trust Fund Ann King

	<p>Ms. King reported that the committee has developed a list of priorities and steps to be taken to get a trust fund. It is important to decide ahead of time how the money would be spent. (See attached handout "Steps Toward Establishing a Brain Injury Trust Fund). Ms. White suggested that Ms. King talk with Michael Eisen at the Division to find out more about legislative activity in alcohol. Chuck Monnett reports that fines and penalties collected from any violation of the penal code must be returned to the county school boards to provide education.</p>				
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Committee will continue meeting	Ana King				

8. Agenda topic: TBI White Paper**Sharon Rhyne**

	<p>Sharon Rhyne stated that now that the Council has been in existence for 3.5 years a "white paper" on the state of brain injury in NC needs to be submitted. She circulated a draft outline of what might be included. The length may be 5-10 pages with a summary sheet. She will need some volunteers to help with the writing. Ms. Farmer will send the "early history on TBI in NC" to Ms. Rhyne. Dr. Hooper will send an article on "State of the State" written by himself and Beth Callahan pre-Council. The paper discussed the status of TBI in NC, unmet needs and why TBI is a significant problem. Dr. Hooper surveyed 500 Psychologists to see what they knew about myths around brain injury. Many of them felt they needed more education. He will send Ms. Rhyne an article from the journal called Exceptionality. Ms. Lash and Dr. Hammond will help with definitions. Jim Swain from VR will help with Vocational Rehab section. Ms. Ellsworth will assist on waiver; Ms. King will help on trust fund and Ms. White will assist with prevention.</p> <p>Target date to send all information to Ms. Rhyne is by Jan. 31, 2008.</p>		
Action Items	Person(s) Responsible	Deadline	
All sections will be sent to Sharon Rhyne for compilation	Members	1-31-08	

9. Agenda topic: General Information**Committee Members**

	<p><u>Committee Reports:</u> <u>Legislative Committee Report:</u> Mr. Swain had to leave early and reported that Ms. Perkins believes this Council needs to develop a long range legislative plan, not just for the next session. Ms. Rhyne reports that her agency (DPH) has already developed a 2 year plan for legislative concerns and the Council needs to meet with Mike Moseley at Mental Health to assist with creating a plan. The Council needs to identify allies, especially now that Senator Kerr is leaving. Ms. Ornitz suggested that once the Council knows who the allies are and where they are from, constituents from their area can begin talking with them. Ms. Ellsworth suggested finding out who is on the Division of MH legislative oversight committee. Legislative committee headed by Ms. Farmer will develop short list of legislative allies by Jan. 31.</p> <p>The Council is not getting administrative help from the Division as there currently is a shortage of staff. Ms. Lash will discuss with Ms. Stein at a future date.</p> <p>Health Services Report: No report at this time.</p> <p>Prevention Committee Report: Liz Newlin, chair of the committee was not present. Ms. White had previously reported on the injury prevention survey.</p>		
Action Items	Person(s) Responsible	Deadline	

Ms. Lash thanked everyone for their participation. There being no further business, the meeting was adjourned at 1:21 pm.